
APPENDIX I

SOURCES OF HEALTH OUTCOME DATA

SOURCES OF HEALTH OUTCOME DATA

SOURCES OF DATA FOR ANALYSIS OF HEALTH OUTCOMES POTENTIALLY AVAILABLE FOR SITE-SPECIFIC POPULATIONS

Routinely
collected
health data

Vital statistics records
Registries
Hospital/medical records
School records

Routinely
collected
population
data

Census data

Non-
routine
health
data

Previously conducted
health studies

VITAL STATISTICS RECORDS

Death Certificate

Nativity Records:

Birth Certificate

Fetal Death Certificate

Ž Completion is a legal requirement

Ž Reporting administered by National Center for Health Statistics (NCHS)

Ž Complete and high quality reporting across U.S. since 1930's

VITAL STATISTICS REGISTRATION SYSTEMS IN THE U.S.

Responsible Person or Agency	Death Certificate	Birth Certificate	Fetal Death Certificate
Physician, other attendant	Completes/ signs medical certification. Sends to funeral director	Completes/ signs medical certificate. Filed with local agency	Completes/ signs medical certification. Sends to funeral director or local agency
Funeral Director	Personal facts. Delivers completed certificate to local agency	xxx	Obtains personal facts Delivers completed certificate to local agency
Local agency(Registrar) or Hlth Dept)	Verifies completeness of certificates Maintains records for local use and reports Sends certificate to state agency		
State agency, Bureau of Vital Statistics	Queries incomplete or inconsistent information Maintains records for state use and reports Transmits records to NCHS		
NCHS	Maintains national records Publishes national statistical reports Maintains technical assistance for quality assurance		

DEATH CERTIFICATE - INFORMATION SYSTEMS MAINTAINED BY VITAL STATISTICS BUREAUS

*Note: Some information may be confidential and only
accessible in summary form*

Local, State, Federal

Hard copy, microfilm/fiche of certificates

State, Federal and Some Local

Computer data tapes

Ž By calendar year of death

Ž Major items coded and entered for each death

Causes of Death Coded Using the International Classification of Disease (ICD)

- Underlying cause of death only (< 1968)
- Multiple causes of death (1968-)

State Federal and Some Local

Published vital statistics reports

(PHYSICIAN, MEDICAL EXAMINER OR CORONER)
U.S. STANDARD

Form Approved
OMB No. 68R 1901

CERTIFICATE OF DEATH

TYPE
OR PRINT
IN
PERMANENT
INK
FOR
INSTRUCTIONS
SEE
HANDBOOK

DECEDENT

IF DEATH
OCCURRED IN
INSTITUTION,
SEE HANDBOOK
REGARDING
COMPLETION OF
RESIDENCE ITEMS

PARENTS

DISPOSITION

CERTIFIER

CONDITIONS
IF ANY
WHICH CAUSE
RISE TO
IMMEDIATE
CAUSE
STATING THE
UNDERLYING
CAUSE LAST

CAUSE OF
DEATH

LOCAL FILE NUMBER		STATE FILE NUMBER	
DECEDENT-NAME FIRST MIDDLE LAST		SEX	DATE OF DEATH (Mo., Day, Yr.)
1. RACE-Is s. White, Black, American Indian, etc. (Specify)		2. AGE-Last Birthday (Yr.)	3. DATE OF BIRTH (Mo., Day, Yr.)
4. CITY, TOWN OR LOCATION OF DEATH		5a. UNDER 1 YEAR MO. DAYS	5b. UNDER 1 DAY HOURS MIN.
7a. STATE OF BIRTH (If not in U.S.A. name country)		7b. CITIZEN OF WHAT COUNTRY	7c. MARRIED, NEVER MARRIED, WIDOWED, DIVORCED (Specify)
8. SOCIAL SECURITY NUMBER		9. USUAL OCCUPATION (Give kind of work done during most of working life, even if retired)	10. KIND OF BUSINESS OR INDUSTRY
11. RESIDENCE-STATE		12. COUNTY	13. CITY, TOWN OR LOCATION
14a. STREET AND NUMBER		14b. INSIDE CITY LIMITS (Specify Yes or No)	15. WAS DECEDENT EVER IN U.S. ARMED FORCES? (Specify Yes or No)
FATHER-NAME FIRST MIDDLE LAST		MOTHER-MAIDEN NAME FIRST MIDDLE LAST	
16. INFORMANT-NAME (Type or Print)		17. MAILING ADDRESS	18. STREET OR R.F.D. NO. CITY OR TOWN STATE ZIP
19a. BURIAL, CREMATION, REMOVAL, OTHER (Specify)		19b. CEMETERY OR CREMATORY-NAME	19c. LOCATION CITY OR TOWN STATE
20a. FUNERAL SERVICE LICENSEE OR Person Acting As Such (Signature)		20b. NAME OF FACILITY	20c. ADDRESS OF FACILITY
21a. To the best of my knowledge, death occurred at the time, date and place and due to the causal stated (Signature and Title)		21b. DATE SIGNED (Mo., Day, Yr.)	21c. HOUR OF DEATH
21d. NAME OF ATTENDING PHYSICIAN IF OTHER THAN CERTIFIER (Type or Print)		21e. M	21f. M
21g. NAME AND ADDRESS OF CERTIFIER (PHYSICIAN, MEDICAL EXAMINER OR CORONER) (Type or Print)		21h. ON	21i. AT
22. REGISTRAR		DATE RECEIVED BY REGISTRAR (Mo., Day, Yr.)	
23. IMMEDIATE CAUSE (ENTER ONLY ONE CAUSE PER LINE FOR (a), (b), AND (c))		Interval between onset and death	
24a. (a) DUE TO, OR AS A CONSEQUENCE OF		Interval between onset and death	
24b. (b) DUE TO, OR AS A CONSEQUENCE OF		Interval between onset and death	
24c. (c) DUE TO, OR AS A CONSEQUENCE OF		Interval between onset and death	
25. OTHER SIGNIFICANT CONDITIONS-Conditions contributing to death but not related to cause given in PART I (a)		26. AUTOPSY (Specify Yes or No)	27. WAS CASE REFERRED TO MEDICAL EXAMINER OR CORONER (Specify Yes or No)
28a. ACC. SUICIDE, HOM. UNDET. OR PENDING INVEST (Specify)		28b. DATE OF INJURY (Mo., Day, Yr.)	28c. HOUR OF INJURY
28d. INJURY AT WORK (Specify Yes or No)		28e. PLACE OF INJURY-At home, farm, street, factory, office building, etc. (Specify)	28f. DESCRIBE HOW INJURY OCCURRED
28g. LOCATION		28h. STREET OR R.F.D. NO.	28i. CITY OR TOWN STATE

INFORMATION OF RELEVANCE ON DEATH CERTIFICATES:

A standard certificate is prepared by NCHS, but some items vary by state.

Health information:

Completed by physician or legal authority such as coroner, medical examiner

Part I Immediate Cause: Enter only one cause per line

(a)

Due to or as a consequence of

(b)

Due to or as a consequence of

(c)

Part II Other significant conditions

Autopsy

Yes/No

Acc, suicide
homicide or
pending

Date of
injury

Hour of
injury

How injury
occurred

ASSIGNING CAUSE OF DEATH:

Line:

- (a) Immediate cause
- (b) Antecedent condition, if any, that gave rise to (a)
- (c) Antecedent condition, if any, that gave rise to (a) and (b)

The underlying cause, the last listed condition, is the disease or injury that initiated the sequence of morbid events leading directly or indirectly to death.

OTHER RELEVANT INFORMATION ON DEATH CERTIFICATES

Date of death

Age at death

Sex

Race

Residence - state, county, city, street address

Marital status

Usual occupation, kind of business/industry

Place of death - town, hospital

INTERNATIONAL CLASSIFICATION OF DISEASES (ICD)

Standardized coding system for causes of death and morbidity under auspices of World Health Organization.

ICD Code Major Category

001-139	Infectious disease
140-239	Neoplastic diseases
240-279	Endocrine, metabolic immune disorders
280-289	Diseases of blood and blood organs
290-319	Mental disorders
320-389	Diseases of central nervous system
390-459	Diseases of circulatory system
740-759	Congenital anomalies
760-779	Conditions originating in perinatal period
780-799	Ill-defined conditions
800-999	Accidents, injuries and poisoning

MAJOR USE OF DEATH CERTIFICATE DATA

- Ž Analysis of patterns of causes of death for residents of geographic areas

Advantages of Analysis of Death Certificate Data:

- Ž Economical and efficient
- Ž All deaths registered
- Ž Comparisons among local areas, states and nationally
- Ž Comparisons by sex, age, race, time period
- Ž Available over many decades
- Ž Good representation of patterns for diseases that are highly, rapidly fatal and readily diagnosed

Disadvantages of Analysis of Death Certificate Data:

- Ž Inaccuracy of physician's assignment of cause of death and ICD coding
- Ž Local and temporal variations in physicians' practice of assigning cause of death
- Ž Poor representation of patterns for diseases that are not highly and rapidly fatal or readily diagnosed
- Ž Inadequate for conditions which do not cause death
- Ž Disaggregation of deaths to small geographic areas may not be possible from computerized data
- Ž Residence based on last residence (at time of death)

BIRTH CERTIFICATE INFORMATION SYSTEMS MAINTAINED BY VITAL STATISTICS BUREAUS

*Note: Some information may be confidential and
only accessible in summary form*

Local, State, Federal

Hard copy, microfilm/fiche of certificates

State, Federal and some Local

Computer data tapes

Ž By calendar year of deaths

Ž Major items coded and entered for each birth

Ž Congenital abnormalities coded by ICD-CM

State, Federal and Some Local

Published vital statistics reports

INFORMATION OF RELEVANCE ON BIRTH CERTIFICATE

A standard certificate is prepared by NCHS, but some items vary by state authority.

Health information:

Completed by physician or non-physician
attendant

Birth weight - (low birthweight)

Estimated gestational age - (premature)

APGAR scores

Congenital malformations or anomalies

Complications of pregnancy

Mother's reproductive history

Demographic Information:

Date of Birth

Sex

Race/Hispanic origin

Residence of mother at time of birth - state,
county, town, street address

Age of mother, father

Occupation of mother, father

TYPE
OR PRINT
IN
PERMANENT
INK
FOR
INSTRUCTIONS
SEE
HANDBOOKU.S. STANDARD
CERTIFICATE OF LIVE BIRTH

LOCAL FILE NUMBER

BIRTH NUMBER

CHILD

1. CHILD-NAME FIRST MIDDLE LAST	2. SEX	3a. DATE OF BIRTH (Mo., Day, Yr.)	3b. HOUR
4a. HOSPITAL-NAME (If not in hospital, give street and number)	4b. CITY, TOWN OR LOCATION OF BIRTH	4c. COUNTY OF BIRTH	

CERTIFIER

5a. (Signature) CERTIFIER-NAME AND TITLE (Type or print)	5b. DATE SIGNED (Mo., Day, Yr.)	5c. NAME AND TITLE OF ATTENDANT AT BIRTH IF OTHER THAN CERTIFIER (Type or print)
5d. REGISTERAR	5e. MAILING ADDRESS (Street or R.F.D. No., City or Town, State, Zip)	

MOTHER

6a. (Signature) MOTHER-MAIDEN NAME FIRST MIDDLE LAST	6b. DATE RECEIVED BY REGISTRAR (Month, Day, Year)
7a. RESIDENCE-STATE COUNTY CITY, TOWN OR LOCATION	7b. AGE (at time of this birth) 7c. STATE OF BIRTH (If not in U.S.A., name country)
8a. STREET AND NUMBER OF RESIDENCE	8b. INSIDE CITY LIMITS (Specify yes or no)
9. MOTHER'S MAILING ADDRESS-If same as above, enter Zip Code only	

FATHER

10a. FATHER-NAME FIRST MIDDLE LAST	10b. AGE (at time of this birth)	10c. STATE OF BIRTH (If not in U.S.A., name country)
11a. (Signature of Father or other informant)	11b. RELATION TO CHILD	

INFORMATION FOR MEDICAL AND HEALTH USE ONLY

12. RACE - MOTHER (e.g., White, Black, American Indian, etc.) (Specify)	13. RACE - FATHER (e.g., White, Black, American Indian, etc.) (Specify)	14. BIRTH WEIGHT	15a. THIS BIRTH - Single, twin, triplet, etc. (Specify)	15b. IF NOT SINGLE BIRTH - Born term, second, third, etc. (Specify)	16. IS MOTHER MARRIED? (Specify yes or no)
17. PREGNANCY HISTORY (Complete each section)		18. EDUCATION - MOTHER (Specify only highest grade completed)		19. EDUCATION - FATHER (Specify only highest grade completed)	
20. LIVE BIRTHS (Do not include this child)		21. DATE LAST NORMAL MENSTRUATION BEGAN (Month, Day, Year)		22. MONTH OF PREGNANCY PRENATAL CARE BEGAN (First, second, etc. (Specify))	
23. OTHER TERMINATIONS (Spontaneous and induced)		24. PRENATAL VISITS Total number (If none, so state)		25. APGAR SCORE 1 min 5 min	
26. DATE OF LAST LIVE BIRTH (Month, Year)		27. COMPLICATIONS OF PREGNANCY (Describe or write "none")		28. CONCURRENT ILLNESSES OR CONDITIONS AFFECTING THE PREGNANCY (Describe or write "none")	
29. COMPLICATIONS OF LABOR AND/OR DELIVERY (Describe or write "none")		30. CONGENITAL MALFORMATIONS OR ANOMALIES OF CHILD (Describe or write "none")			

DETERMINE
ONE YEAR OF
AGE
Enter State File
Number of death
certificate for this
childMULTIPLE BIRTHS
Enter State File
Number for maternal

LIVE BIRTH(S)

FETAL DEATH(S)

MAJOR USE OF BIRTH CERTIFICATE DATA

Ž Analysis of patterns of health information on newborns to residents of geographical areas

Advantages of Analysis of Birth Certificate Data:

- Ž Economical and efficient
- Ž Birth registration is mostly complete
- Ž Comparisons among local areas, states and nationally
- Ž Comparisons by maternal age, race, time period
- Ž Available over many decades
- Ž Good representation of patterns for
 - Ž Birth weight
 - Ž Severe birth defects readily diagnosed at birth, e.g., anencephaly or spina bifida

Disadvantages of Analysis of Birth Certificate Data:

- Ž Inaccuracies and incompleteness in information such as gestational age, APGAR score, mother's reproductive hx, complications of pregnancy
- Ž Local and temporal variations in physicians' practice of recording of other congenital malformations
- Ž Disaggregation of births to small geographic areas may not be possible from computerized data
- Ž Residence at birth may not be residence throughout pregnancy

FETAL DEATH CERTIFICATES

Fetal Death:

Death prior to complete expulsion or extraction of fetus

Legal certification requirements vary by state:

Most require certification after 20 weeks gestation.

Some require certification regardless of gestation age

Note:

Ž Certification nearly complete for > 28 weeks gestation

Ž Certification inconsistent for 20-28 weeks

Ž Certification incomplete for <20 weeks

FETAL DEATH CERTIFICATE

A standard certificate is prepared by NCHS, but some items vary by state adoption. Completed by physician or non-physician attendant.

Health Information:

Cause of death - fetal/maternal conditions

Gestational age

Congenital malformations or anomalies

Demographic Information:

As above

USES OF FETAL DEATH CERTIFICATES RESTRICTED BY COMPLETENESS OF REPORTING

(with reporting as noted above)

Ž Analysis of patterns of fetal deaths > 28 weeks
gestation by geographic areas

Disadvantages:

Ž Incomplete reporting <28 weeks gestation
Ž Incomplete reporting of congenital
malformations

DISEASE REGISTRIES

- Ž Centralized information collection systems, typically established under the authority of local, state or federal health agencies
- Ž Have a mechanism to identify persons diagnosed with given diseases in their population coverage area

Mechanism:

- Ž Medical care providers may report to registry
- Ž Registry staff may actively review medical records
- Ž Disease diagnosis, demographics and other information collected on each case

Data stored centrally by registry:

- Ž Hard copy, microfilm/fiche of abstracts (forms)
- Ž Computerized data files
- Ž Published reports

CANCER REGISTRIES (OR TUMOR REGISTRIES)

- Ž Operating in 43 states, District of Columbia and Puerto Rico, where population coverage may be statewide or regional
- Ž Objective is complete identification within their coverage area of all new diagnoses of cancer (typically exclusive of non-melanoma skin cancers) soon after diagnosis (incident cases of cancer)
- Ž Operationally to identify newly diagnosed cancer cases
- Ž May be legal requirement for reporting
- Ž Hospitals may report cases or registry staff may review hospital records
- Ž Typically a strong emphasis placed on completeness of identification of cases and data quality
 - Ž Eliminate duplicate reports
 - Ž Standardized reporting forms
 - Ž Diagnostic criteria
 - Ž Additional checks via death certificates
 - Ž Eliminate non-residents

INFORMATION OF RELEVANCE ROUTINELY COLLECTED BY CANCER REGISTRIES

Health Information:

Information is taken from hospital and clinic records including laboratory (pathology, CT scans, x-rays, cytologic) reports. The diagnosis of site/type of cancer is clinical judgment.

Ž Site/Type of Cancer

Ž Staging of Cancer

Ž ICD-CM code

Ž Primary vs. Metastatic

Demographic/Other Information:

Date of initial diagnosis

Sex

Age at Dx

Race/Ethnic grouping

Usual Occupation

Residence at Dx: State, County, Town, Street
Address

CANCER SURVEILLANCE, EPIDEMIOLOGY AND END RESULTS PROGRAM (SEER)

Operated under auspices of National Cancer Institute and Centers for Disease Control since 1973. SEER aggregates cancer data from eight cooperating registries - (SEER Sites):

California

Connecticut

Georgia

Hawaii

Iowa

Michigan

New Mexico

Utah

Washington

These aggregated data are used for estimate of national cancer incidence.

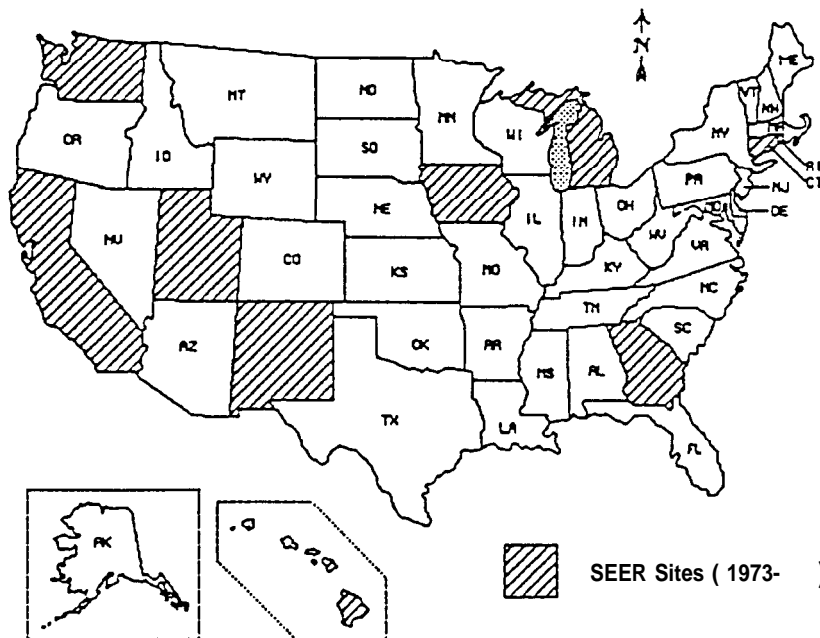
STATES WITH CANCER REGISTRIES

(State-wide or Regional Coverage)

SEER
Sites
(1973-)

California
Connecticut
Georgia
Hawaii
Iowa
Michigan
New Mexico
Utah
Washington

Registries in 43 states
and in District of
Columbia and Puerto Rico



MAJOR USE OF CANCER REGISTRY DATA:

- Ž Analysis of patterns of newly diagnosed cancer (by type or all) among geographic areas

Advantages of Cancer Registry Data:

- Ž Economical and efficient
- Ž Registry typically complete for severe cancers
- Ž Comparisons by age, sex, race
- Ž Focus is newly diagnosed disease (not just death due to cancer) so not influenced by survival

Disadvantages of Cancer Registry Data:

- Ž Not available in all areas of U.S.
- Ž Time period covered may be short in some areas
- Ž Disaggregation to small localities may not be possible from computerized files
- Ž Accuracy of clinical diagnosis may be unreliable and vary across areas
- Ž Completeness of ascertainment (may vary across areas and over time due to screening for early diagnosis)

BIRTH DEFECTS REGISTRIES

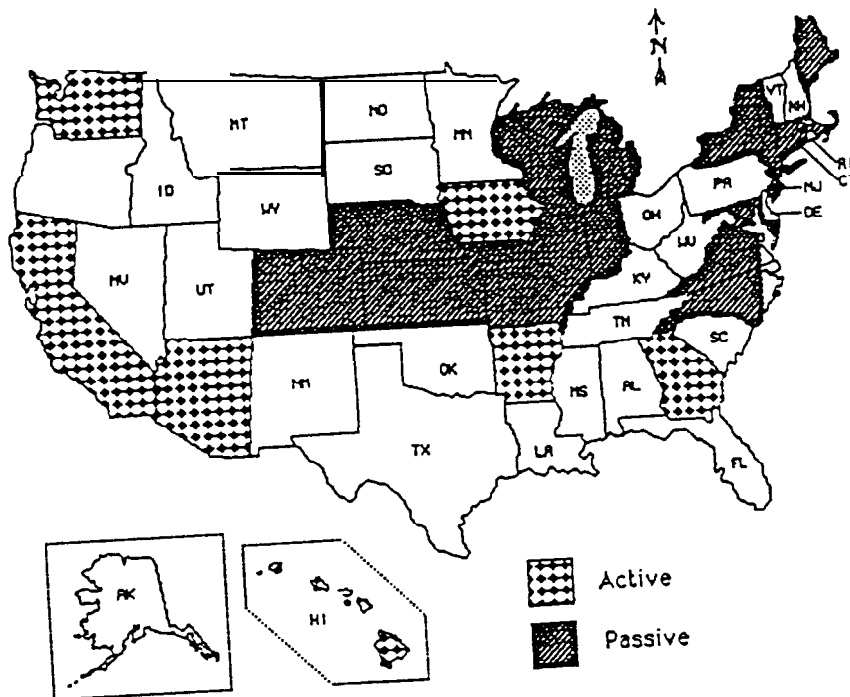
Atlanta, GA: Metropolitan Atlanta Congenital Defects Programs (MACDP) under auspices of CDC (1967-)

Intensive monitoring of the diagnosis of congenital malformations among liveborn or stillborn infants with structural, chromosomal or biochemical abnormality presumed present at birth and diagnosed prior to one year of age.

The operating systems are similar to those of cancer registries, however, the identification of children with birth defects may be incomplete and/or inaccurate as to diagnosis. Some registries may not have long been in operation.

(State-wide or Regional Coverage)

Arkansas
Arizona
California
Georgia
Hawaii
Iowa
Washington



OCCUPATIONAL DISEASE REGISTRIES

Some 60% of states have either mandatory or voluntary reporting programs (reporting to State Health Agency) of selected occupational health conditions, e.g., lead poisoning, silicosis, and asbestosis.

Disadvantages:

- Ž not all industries covered
- Ž reporting may be grossly incomplete and vary in completeness by area
- Ž diagnostic criteria are not standardized

National Institute of Occupational Health and Safety (NIOSH)

- Ž putting into operation a mandatory reporting system nationwide for 10 leading work-related diseases and injuries
- Ž quality of reporting and work-force coverage are yet to be established

MEDICAL RECORDS

Hospital records

Ž In-patient

Ž Emergency room

Physician and Clinic Records

School Nurses' Records

Industrial Facility Employee Records

Medical Records:

Type	Centralized Authority	Information System Computerized	System Hard Copy	Confidentiality Issues	Other Issues
Hospitals Inpatient	No	Discharge Diagnostic Indexes	Yes by Discharge Diagnosis	Yes	Variation in hospitalization Catchment patterns Quality of clinical diagnoses
Emergency Room	No	Atypical to Arrange by Disease	Yes Rarely Arranged by Disease	Yes	Variation in utilization ER Catchment patterns Quality of clinical diagnosis
Physician /Clinics	No	Atypical to Arrange by Disease	Yes Rarely Arranged by Disease	Yes	Variation in utilization Catchment patterns Quality of clinical diagnosis
School Nurses Records	Rare	Rare	Yes Rarely Arranged by Disease	Yes	Variation in utilization Quality of diagnosis
Industrial Facility Employee Records	No	Rare Atypical to Arrange by Disease	Yes Rarely Arranged by Disease	Yes	Variation in utilization Quality of diagnosis

MEDICAL RECORDS MAJOR USE:

- Ž Allow for analysis of disease patterns in geographic areas

Advantages:

- Ž Analysis of diseases that are not target of previously described systems

Disadvantages:

- Ž Typically uneconomical and inefficient unless few providers in an area
- Ž Authorization required
- Ž Difficult to define catchment population as utilization patterns not residentially bound
- Ž Utilization of medical care influenced by
 - Ž disease severity
 - Ž insurance coverage
 - Ž accessibility
 - Ž physician practices
 - Ž personal preferences
- Ž Quality of clinical diagnosis variable
- Ž Demographic characteristics hard to obtain
- Lack of available comparative data

MEDICAL RECORDS NATIONAL DATA SYSTEMS

**NCHS National Hospital Discharge Survey
(1970-)**

Summary data on sample of U.S. hospital discharges

Ž Diagnoses, surgical procedures, patient characteristics

426 hospitals in sample, covering >200,000 discharges/yr

Commission on Professional and Hospital Activities (CPHA):

About 40% of U.S. hospitals utilize service for compiling data on patient discharge diagnoses and characteristics. Data for a 1% representative sample of U. S. hospitals also reported (1980-).

NCHS National Ambulatory Medical Care Survey:

A sample of 3000 private physicians who voluntarily report on diagnoses and characteristics of patients office visit during a one-week period.

CENSUS DATA

Provides information on the number of persons and demographic characteristics of persons residing in geographic areas.

Major sources of census data:

- 1. U.S. Bureau of Census** - conducts total enumeration of U.S. population by age, sex, residence, race/ethnicity, education, occupation status every 10 years.

Census data are available in publications and in computerized format through various repositories. State health departments and some local agencies maintain census data for their areas.

Census data can be disaggregated at various levels: national, regional, states, counties, cities, census tracts, and blocks.

Disaggregation for smaller subdivisions such as census tracts or blocks may not be possible for rural areas.

The Bureau of the Census has also devised a system that is linked to latitude and longitude crosspoints. These grids can be aggregated into special areas of interest which do not strictly comply with census units.

2. Population estimates between national censuses are also prepared and published. Some estimations are based on analysis of patterns such as housing starts, utilities, tax returns, school registration, etc. Other methods are also employed. Intercensal estimates obviously are less reliable than the U.S. Census counts, may be limited to certain areas and may not hold for small subdivisions within larger areas. Such estimates are typically available from state health agencies, governmental planning agencies, etc.